



August 5, 2009

Secretary Kathleen Sebelius
Department of Health and Human Services
Centers for Disease Control and Prevention
Division of Global Migration and Quarantine
1600 Clifton Road, NW
Atlanta, GA 30333

Re: CDC-2008-0001

Medical Examination of Aliens – Removal of Human Immunodeficiency Virus (HIV)
Infection from Definition of Communicable Diseases of Public Health Significance

Dear Secretary Sebelius,

Thank you for the opportunity to submit comments on the proposed rule regarding "Medical Examination of Aliens – Removal of Human Immunodeficiency Virus (HIV) Infection from Definition of Communicable Diseases of Public Health Significance." Our organizations represent the national and international communities of people affected by hemophilia, von Willebrand Disease and other bleeding disorders. The National Hemophilia Foundation (NHF) is the largest US health care advocacy organization serving the needs of individuals with bleeding and clotting disorders. The World Federation of Hemophilia (WFH), an international organization dedicated to improving the lives of people with hemophilia and other inherited bleeding disorders, has member organizations in more than 100 countries including the US and official recognition from the World Health Organization.

Hemophilia is a lifelong, inherited bleeding disorder caused by low levels or absence of a protein called a clotting factor that is essential for blood clotting. This inability to clot occurs in approximately 1 in 10,000 births. It is estimated that over 400,000 people worldwide suffer from hemophilia. As a result of tainted blood and blood products, it is estimated that approximately 10% of the global hemophilia population, as well as some individuals with von Willebrand Disease and other rarer bleeding disorders are infected with HIV.

Our organizations strongly support the Department of Health and Human Service's interest in revising the Part 24 regulation to remove HIV infection from the definition of "communicable disease of public health significance" and to remove testing for HIV from the scope of medical examinations in its regulations. As one of the remaining stigmas of living with HIV/AIDS, repealing this discriminatory ban is a priority for our organizations. The proposed rule must be enacted so that this unjust policy can be eliminated. This discrimination against people living with HIV and AIDS is inexcusable, and the policy has serious consequences.

The current requirements for travelers with HIV to come to the US are particularly difficult for people with both hemophilia and HIV. For example, travelers with HIV must bring an adequate supply of antiviral therapy and have sufficient assets or insurance to cover any medical care that

they may need while in the US. Depending upon their country of origin, some people with hemophilia and HIV will likely be traveling with antiviral drugs and clotting factor, the medications used to treat these diseases. However, due to the high cost of treatment, it is unlikely that any but the wealthiest people could attest that they could fully cover the cost if an accident or medical crisis were to occur while visiting the United States. While participants attending national and international bleeding disorder conferences are encouraged to purchase travel insurance, most plans do not cover pre-existing conditions. People affected by a bleeding disorder would likely not be able to meet these conditions. International visitors living with a bleeding disorder should not be singled out due to their having a bleeding disorder and/or HIV.

The proposed rule would also remove testing for HIV from the scope of medical examinations in its regulations. We support this, as well, because there are significant privacy concerns with HIV testing in home countries. Many individuals do not disclose their HIV status in their home countries for fear of discrimination. Unfortunately, stigma attached with living with HIV remains pervasive and fear of losing one's employment, family, and opportunities for education are very real in many parts of the world. Without an absolute guarantee that an individual's HIV status will not be disclosed, HIV testing in the home country would remain a barrier to travel.

Not only is the ban on visitors with HIV problematic for the international bleeding disorders community, but the bleeding disorders community in the US is also negatively affected. Every two years, the WFH holds an international Congress, the leading global meeting for patients with bleeding disorders, researchers and health care professionals. Due to the significant impact of HIV on the global bleeding disorders community, the United States has been excluded from hosting international meetings of the WFH since the enactment of the travel ban. Thus, patients and health care providers in the United States are missing an important opportunity to collaborate, share knowledge, and learn about the latest research and treatment options. The U.S. has expressed strong interest in hosting the 2014 World Congress. However, for the U.S. to be eligible as a finalist, implementation of the proposed rule must be assured by the selection deadline, 1 February 2010.

In conclusion, we see this proposed rule as essential to ending the discriminatory policy against travelers with HIV and we urge you to implement the final rule as soon as possible. Thank you again for the opportunity to comment on this proposed rule on behalf of individuals with hemophilia, von Willebrand Disease and other bleeding disorders. If you have any questions, please contact _____ with the National Hemophilia Foundation at _____ or _____ with the World Federation of Hemophilia at _____.

Sincerely,

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